



# Whispers on the Web

A Monthly Online Newsletter for WebWhispers

*June 2023*

# From The Editor's Desk

Hello members, and welcome to June 2023 Whispers on the Web.

We can't express enough gratitude toward all those who responded to our What Do YOU Say question this time. Many of you, both new and seasoned members took the time to respond. What an inspiration to hear how your experiences with laryngectomy have equipped you to help others. Thank you!

Speaking of helping others, have you heard of "supportive care?" Hint... it is different than palliative care for some very important reasons. Jessica Latchman, an Advance Practice Registered Nurse at the Moffitt Cancer Center in Florida works in the department of Supportive Care Medicine. She sheds light how supportive care improves quality of life and who it is designed to help.

And finally, you might be wondering what you missed at the 51st annual International Association of Laryngectomees (IAL) Annual Meeting and Voice Institute. Both Tom and Brooke give their perspectives on some of the key moments from St. Louis, along with a sneak peek into next year's meeting (yes, next year already!). Be sure to check it all out in this month's issue and let us know what you think. We hope to hear from you again soon.



## WebWhispers With The International Association of Laryngectomees 2023

The IAL's 2023 Annual Meeting and Voice Institute was attended by many more people than in recent years, many of them first-timers to the event. Under the direction of Caryn F Melvin,

Ph.D., CCC-SLP, the Voice Institute was an exceptional resource for laryngectomees, caregivers, and professionals in the head and neck cancer community. For those in our

## Whispers on the Web June 2023

### Contents

#### From The Editor's Desk

#### The Scuttlebutt

The International Association of  
Laryngectomees 2023

Tom Whitworth

#### VoicePoints

Supportive Care

Jessica Latchman MSN,  
APRN, AGACNP-BC,  
ACHPN, AOCNP

#### Member Contributions

IAL Wrapup

Brooke Elkan-Moore

#### What do YOU Say?

Helping Others  
Members

WebWhispers is an Internet based support group. Please check our home page for information about the WebWhispers group, our email lists, membership, or officers. For newsletter questions, comments or contributions, please write to [editor@webwhispers.org](mailto:editor@webwhispers.org)

Kim Almand, Managing Editor  
Tom Whitworth, Editor

Disclaimer: The information offered via WebWhispers is not intended as a substitute for professional medical help or advice but is to be used only as an aid in understanding current medical knowledge. A physician should always be consulted for any health problem or medical condition. The statements, comments, and/or opinions expressed in the articles in Whispers on the Web are those of the authors only and are not to be construed as those of the WebWhispers management, its general membership, or this newsletter's editorial staff.



community, nothing compares to the IAL Voice Institute. We are already accepting scholarship applications for next year's event. The information is on our website.

On Friday, May 12, more than eighty people attended the WebWhispers 21st Annual Awards Dinner. The pre-dinner reception this year was provided by WebWhispers. The dinner was arranged, as in the past, by Jeff Vanden Hogen, who always does a great job. Susan Reeves, CCC- SLP was featured as guest speaker. The WebWhispers Annual Dinner tradition was instituted by Pat Sanders as an opportunity to express our gratitude to some of those who have served the laryngectomee community in the past year by working with or supporting WebWhispers in some special way and to present WebWhispers scholarships for attendance at the IAL Voice Institute. We also use this time together to remember those who have gone on before us in the previous year. This year we honored 14 WebWhispers members who passed away since our gathering in June of 2022.

Several awards were presented, each celebrating a unique contribution. The following is a recap:

**Volunteer of the Year  
Presented to Jeff Vanden Hogen  
VP-Internet Activities, moderator,  
and so much more**

For your consistent dedication to WebWhispers and all you do for our organization, we are truly grateful!

**Certificate of Appreciation  
Presented to Sherry Martin**

For years of volunteer efforts through Lary's Speakeasy and elsewhere in the midst of her own adversity, all the while setting an example of courage, determination, grace, and love for others

**Certificate of Appreciation  
Presented to Susan Reeves, CCC-SLP**

For many years of service to the laryngectomee community. In every role, you have served with dedication, diligence, and love for laryngectomees. Through your constant presence with the

International Association of Laryngectomees Annual Meeting and Voice Institute, your own practice as an SLP, your leadership, teaching and more, you have made and continue to make a difference in the quality of life for laryngectomees.

With help from Atos Medical, InHealth Technologies, Buck Martin Fund, WebWhispers provided scholarships and sponsorships exceeding \$8,400. The scholarships listed below went to laryngectomees and laryngectomee/caregiver couples, all of whom were first-time IAL Voice Institute attendees.

InHealth Technologies scholarships took the form of paid hotel stays for these couples:

- Sarah Tan & Jonathan Ho- St. Albans, England-UK
- Kevin & Rhonda Williams- Pasco WA

A \$3,000 grant from Atos Medical enabled these laryngectomees and three caregivers to attend the Voice Institute:

- Connie Mueck – Elkhorn, WI \$300
- Don Morgan- Munford, AL \$600
- David Green- South Hutchinson, KS \$300
- Brooke Elkan-Moore- New Windsor, NY \$300
- Joan Krueger- Lake Geneva, WI \$600
- John Kwiatkowski- Loveland, CO \$600
- Roscoe Starek- Alexandria, VA \$300

We are already accepting scholarship applications for next year's event. Please see our website for more information.

And finally, Whispers on the Web is always on the lookout for new writers, whether regulars or occasional contributors. Contact us at editor@webwhispers.org. If you would like to help WebWhispers in some other way, please contact me at tom.whitworth@webwhispers.org

*Enjoy, Laugh, and Learn,  
Tom Whitworth  
WebWhispers President*



*Voice Points is written by professionals for the lary community and is coordinated by Kim Almand M.S, CCC-SLP and Erin Guidera, M.S., CCC-SLP. Please contact them with contributions or questions at [Kalmand@uthsc.edu](mailto:Kalmand@uthsc.edu) or [Erin.Guidera@moffitt.org](mailto:Erin.Guidera@moffitt.org)*

## **Supportive Care: Its Importance in Patient Care**

The term “supportive care” and “palliative care” are used interchangeably in healthcare (Lo & Buss, 2019). They both focus on improving the quality of life for patients and families with serious illnesses. According to the Multinational Association of Supportive Care, supportive care is defined as care delivered to patients with any serious illness at any point along the trajectory of their disease (Berman et al., 2020). It is meant to improve the quality of life of the patient by addressing all domains of care such as physical, psychosocial, spiritual and social aspects (Ferrell, 2019). It is also important to note that supportive care can be used simultaneously with all current therapies a patient may be on and is not limited by their current treatment plans.

Therefore, supportive care is holistic care delivered to patients by a care team comprising of medical providers such as physicians and advanced practice professionals, social workers, chaplains and nurses with the aim to improve or preserve quality of life at any stage of an illness (Ferrell, 2019).

Over the past decade, patients and providers have been found to gravitate to the term “supportive care” as compared to “palliative care.” This is because many patients associate

palliative care with hospice care and end of life (Lo & Buss, 2019). Therefore, many healthcare systems with palliative care teams have now rebranded themselves as “supportive care teams” to enhance their images and deliver much needed care. This has led to greater acceptance by patients and clinicians to include supportive care as part of the treatment team whereby improving patient outcomes (Lo & Buss, 2019).

In addition, as there continues to be an exponential growth in our aging population, as well as advances in immunotherapy and targeted therapies for numerous chronic ailments such as cancer, supportive care is becoming an ever-important aspect in patient care (Berman et al., 2020). However, despite these advances in therapy, many of these novel treatment options have resulted in significant toxicities to patients. This has led to increased symptom burden and overall poor quality of life for patients.

Therefore, in order to improve survival rates and obtain better outcomes, there has been a global movement to include supportive care as an integral part of treatment pathways. This would enhance care coordination, and quality indicators for patients (Berman et al., 2020).

In fact, recent studies have shown that patients

who have supportive care or palliative care integrated early on in their disease trajectory, had overall better patient outcomes when compared to standard care (Temel et al., 2017). Other factors such as mood, trust and rapport with their providers were positively impacted (Temel et al., 2017).

Supportive care is not only aimed at symptom management for patients to tolerate their current treatment plans but to also improve the overall quality of life for patients by utilizing a holistic approach to care. This care addresses the psychosocial, spiritual and physical aspects of suffering (Ferrell, 2019). However, many patients continue to have limited access to this type of service despite its importance to patients' care. Future healthcare policies and provider goals should be directed at increasing access to palliative care for all patients despite their type of disease or physical location.

**Jessica Latchman MSN,  
APRN, AGACNP-BC,  
ACHPN, AOCNP**

*Jessica is an Advanced Practice Registered Nurse specializing in palliative medicine in the Moffitt Cancer Center Department of Supportive Care Medicine. She has been practicing as a nurse practitioner at Moffitt for 12 years in palliative care. Jessica earned her undergraduate and masters' degree in nursing at the University of South Florida, Tampa. She also has a degree in chemical engineering from the University of South Florida. She is board certified by ANCC, Hospice and Palliative Nurses Association and the Oncology Nursing Certification Cooperation and licensed by the State of Florida Board of Nursing. Jessica has published numerous articles and plays an active role in the training of advanced practice professionals, fellows and medical students. Jessica is currently pursuing her Doctor of Nursing Practice degree at the University of South Florida.*

## References:

Berman, R., Davies, A., Cooksley, T., Gralla, R., Carter, L., Darlington, E., Scotté, F., & Higham, C. (2020). *Supportive Care: An Indispensable Component of Modern Oncology*. *Clin Oncol (R Coll Radiol)*, 32(11), 781-788. <https://doi.org/10.1016/j.clon.2020.07.020>

Ferrell, B. (2019). *National Consensus Project Clinical Practice Guidelines for Quality Palliative Care: Implications for Oncology Nursing*. *Asia Pac J Oncol Nurs*, 6(2), 151-153. [https://doi.org/10.4103/apjon.apjon\\_75\\_18](https://doi.org/10.4103/apjon.apjon_75_18)

Lo, S., & Buss, M. (n.d.). *What is the difference between supportive and palliative care?* *American Society of Clinical Oncology*. Retrieved April 27, 2023, from <https://dailynews.ascopubs.org/do/difference-between-supportive-and-palliative-care>

Temel, J. S., Greer, J. A., El-Jawahri, A., Pirl, W. F., Park, E. R., Jackson, V. A., Back, A. L., Kamdar, M., Jacobsen, J., Chittenden, E. H., Rinaldi, S. P., Gallagher, E. R., Eusebio, J. R., Li, Z., Muzikansky, A., & Ryan, D. P. (2017). *Effects of Early Integrated Palliative Care in Patients with Lung and GI Cancer: A Randomized Clinical Trial*. *J Clin Oncol*, 35(8), 834-841. <https://doi.org/10.1200/jco.2016.70.5046>



## International Association of Laryngectomees: Voices over Saint Louis

Brooke Elkan-Moore

For 3 ½ days there were more voices of laryngectomees from TEP, to electrolarynx, to esophageal and augmentative communication raised through the Halls of the Sheraton Lakeside Chalet than most of us had ever heard in one place before. With an age range of mid-80s to a wonderful young boy of 6, with years as a lary from over 45 to less than one we were a tribe of fierce and fabulous warriors carrying forth our message that we may breathe through our necks, but we are completely who we are!

As a first timer I had only a bit of an idea of what the experience might be, and it was so much more than I had imagined. Seeing in person and speaking directly with those I had met on Zoom meetings and in Facebook (FB) groups who had helped me so much in the past was incredible. To put full face and personality to so many was wondrous.

Our community is full of astonishing people who are committed to helping others and to showing how living fully with a life changing, but more importantly, life-preserving surgery can be done with grace, with hope, with courage and with a deep appreciation of the gifts we have.

As always, the kindness of our community shone through as so many reached out and offered assistance in helping others to find and embrace a voice. Tony, as the master of EL so gently and with such compassion helped one young woman with her voice so that others could hear her and fully understand all she had to communicate.

Hearing someone speak with confidence using esophageal speech for the first time was so thrilling. The workshops offered to try this method of communication were just so impressive. Most everyone-not me unfortunately- was able to make sounds, say a few words and get the practice assignment for the sessions to come on FB.

The programs offered in the Voice Institute were well attended by laryngectomees as well as SLPs and graduate students. Having the opportunity to get clear and well documented information on so many topics was a great benefit to care givers and patients alike. So many of us were happy to share our first neck experiences and find humor and pathos in the stories we shared.

I do need to say sorry to the SLP student who was horrified to see me use the blue brush with no mirror or light to clear my TEP. I am sure that she had only ever seen it demonstrated in full equipment mode with lights, mirrors and slow steady hands. I am one of those people who has horrible left/right perception and mirror images are just about unintelligible to me. In the hospital the mirror was too high for me to see much in my stoma so I adapted by imagining the space where the TEP was and then inserting the brush. I was more accurate that way than when using a mirror. It also eliminates the gag reflex that I do get when I see the brush go into the TEP. Good thing no one tested me before or I might not have gotten one. She bolted from the restroom before I could tell her it was OK!



## How has your experience with laryngectomy equipped you to help others?

Hello, my name is Billie. I am my husband's caregiver. He had his laryngectomy on Aug 8, 2022. I'm a CNA for 27 years and when Jeff had his surgery, I had never taken care of a laryngectomy patient before. It was all new. In the past 8.5 months, it feels like I've done this forever. I've always been the one to help. I cared for my grandpa and uncle during their time of need (non-laryngectomy) and many, many nursing home patients. In the beginning I was kind of scared about him coming home and having to help. I didn't know what to do, but one day at a time and lots of reading and our favorite Facebook groups. I did know not to let us keep going backwards. Every day is a new day to keep moving forward. Today, he is doing wonderful, just a few hiccups along the way.

– Billie Trail

My voice handicap gives me a better understanding and compassion to other people's handicaps. And remembering that just a few years ago I had a normal human voice reminds me that many of us weren't born with our handicaps, that we had to learn to overcome them.

– David Smith

I have been a volunteer all my life. My parents did it and I followed their lead. My parents equipped me to help others, and my actions as an adult has equipped me as well. I see all types of people in and around my circle of friends

and acquaintances, and I truly believe that volunteerism, from a truly altruistic approach, makes people happier than those who don't volunteer. It's never too late to start, and if your family was not role models and you are hesitant, join a friend who volunteers. Watch and learn, and then find a cause you are passionate about.

– Kevin Williams

I biggest thing I do for larynx cancer patients is I visit them in the hospital. I am a living and believable proof that you can get through this and come out the other side almost able to do everything they could before becoming a lary. I give them lots of information (such as the IAL's "First Steps." But the most important message I deliver is "hope." I know in almost all cases I relieve fear and anxiety. I leave them almost always with a smile on their faces and a belief that they also can get through this.

– David Blevins

I am more aware of others' health issues and try to be sympathetic to their concerns.

– Dick Sipp

I was an umpire before I became a laryngectomee. I knew that I would not be able to continue to umpire after my surgery. I was OK with that for a week or two. Then I decided to see if I could come up with a way to voice my umpire calls. I used a couple of sound boards with switching for 22 umpire calls. That allowed me to continue doing what I enjoyed.

What I did to help others, is I was able to make one for another "Lary" umpire. That in itself was very rewarding. Helping someone else is the greatest thing we can do.

– Glen Van Hill

There are one or two positives about my Laryngectomy. I have met so many people all over the world that have become friends because of it. All of these people have helped me and taught me a lot about living with a Laryngectomy and how to help others. Through this channel I have a lot of ways I help new Laryngectomees. I do visits



both before and after their surgery and keep in touch with several. At the IAL conferences one of the most fun things is to talk to the new SLP's who have never experienced a Laryngectomy. Being a lary to me was a beginning of a new normal not just thinking about what I lost.

– David Kinkead

July 30th, 2013. Almost 10 years.

I became a lary October 21, 2019. While in the hospital, I was non-vocal and communicated primarily with pen and paper. A respiratory technician saw some of my notes and asked if he could borrow them, as he thought that they might help some of his patients. His suggestion and these notes became my first book, which I now give away to new larys, to caregivers, to those facing the possibility of the surgery, to SLP's, and to anyone else interested in finding out more about the subject. Since one of my aims was to raise awareness, I also developed a line of decorative stickers that I wear on my HME; not only to decorate it, but also to call attention to it. I also give these away to any lary who wants some of them. I am and have been auditioning for game shows, so that I can present the public with a positive image of an HNC survivor and warrior. I have also applied to TED Talks. For the last two years, I have also been a mentor for SLP students at the request of Caryn Melvin.

–Aaron Wayne

As a member of The New Voice Club of Oregon, it is a good feeling to help others with my experiences. We often see new laryngectomees attend a meeting soon after their recent surgery. While they are usually a bit downcast and dreading the future, they soon get energized when they see us talking and discussing activities we are doing. The "Tips & Tricks" I share from my 12 years as a lary are always well received.

– Pete Mueleveld

I have been a laryngectomee for over 26 years. I have served as a peer counselor for the Voice Clinic at Vanderbilt University Medical Center for several years working with pre and post laryngectomy patients. I can be reached by email: [mgm0042@comcast.net](mailto:mgm0042@comcast.net) or phone: 615-

364-6973. Will be glad to help however I can.

– Marvin "Sonny" Meiggs

I would say if anything, my experiences with having a laryngectomy have given me a perspective on having to overcome physical and emotional adversity and letting others know, through perseverance, you can overcome most anything. Even though I, like most of you, have my days of frustration and stress of having to cope with life differently than others, I can offer advice on relying on yourself to pick oneself up and march forward. Also, give others credit and don't sell people short. There are still very many caring people in this world of ours. Life is full of twists and turns, sometimes cruel and tough to deal with, but God has a bigger plan and uses each of us to carry out that plan for his purpose.

– John Hendrix 8/3/2011

I have actually mentored 2 gentlemen who did not have laryngectomies but were considering it. One gentleman had a trach first and was non-vocal and on a feeding tube. He can now speak with a TEP and is once again eating. The other gentleman had a laryngectomy but was not familiar with TEP. He ended up with a TEP and was able to communicate with his family and grandchildren for 3 years before he passed away from a non-related illness. My lary experience basically allowed me to communicate with both gentlemen and their families in a manner that a non-lary would not understand well so, yes, I consider myself better equipped now.

– Don Patton

